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### **FOREWORD**

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### INTRODUCTION

### **Background**

Although Hispanic women have lower rates of breast cancer, they present at a later stage with a poorer prognosis for survival. Ethnic differences in stage at diagnosis may be explained in part by the lower participation of Hispanic women in breast cancer screening. Hispanic women have been targeted as a special population group under the nation's health care objectives for the year 2000. A year 2000 goal is to increase their rate of receiving biennial mammograms to 60 percent for women 50 years and older.

Two hypotheses have been proposed to explain the under-utilization of preventive services in general among Hispanics. One attributes it to problems with access, such as lack of health insurance or having no usual source of care, which are more prevalent in the Hispanic population. The second attributes it to acculturation or the process of change that individuals undergo (in terms of language, attitudes and personality) as they are exposed to a new culture. This hypothesis argues that the more acculturated one becomes the more likely he(she) is to utilize health services.

A number of studies have examined determinants of mammographic screening behavior among Hispanic women [2-14], but few have focused on the older age group [3-6,10]. Subjects in these studies were predominantly Mexican American residents of urban areas. Mammographic screening was found to increase with age [4,11,14] and educational attainment [4] and breast cancer knowledge [14]. It was greater for measures of access to care - having a regular doctor [3] and transportation services [3] - and engaging in preventive health behaviors [3]. Ethnic differences may disappear when controlling for demographic and other factors [9-11], but may also remain as an independent predictor of screening behavior [12-13]. When acculturation had a significant effect, it was attributed either to language preference [2,6] with Spanish language usage interpreted as a barrier to access [1]. Or, it was also attributed to strong attitudes towards traditional family structure with familism in the less acculturated group providing a positive influence on behavior. [8].

Other research involving Mexican American women in Texas suggests that familism may also be an important factor in reinforcing or hindering screening behavior [8,15,16]. Familism is a central value to the Mexican American culture [17-20] and refers to the "strong identification and attachment of individuals to their families" [20]. Members of Hispanic families have strong feelings of loyalty and a commitment to provide emotional and material support to others within the family. They also have a strong commitment to extended family relationships and rely on family members in time of need. Three dimensions to familism have been identified [20]: 1) familial obligations; 2) perceived support for the family; and 3) family as referents. Perceived support for family members remains unchanged with increased acculturation while the other dimensions decrease [20].

While familism is a value shared with other cultures, high familism is a particularly distinct and important characteristic in Hispanic groups. It is generally seen as a positive influence by providing a buffer against physical and emotional stress [21]. Family responsibilities, however, may also produce adverse effects such as depression in the elderly [22]. It may also inhibit the acceptance of medical practices and act as a barrier to health services utilization [23].

The effect of familism on utilization of health services, however, may be a function of the care being sought. Frequency of family contacts was found to be positively related to seeking prenatal care early in pregnancy but negatively related to consulting with a physician when ill [15]. Further evidence of the reinforcing role of familism in preventive care is found in a study of breast cancer screening participation among Texas women [16]. Among Hispanic women who participated in the screening program 27 percent cited "pressure from family" as an important factor in their decision to participate.

These studies and the familistic orientation of the Mexican American culture suggest that breast cancer screening among older Hispanic women might be enhanced through family oriented interventions. In Mexican American families, relationships between mothers and daughters and other female members are particularly close [17] and could be used to promote mammographic screening across generations. Family focused interventions based on female relationships is further supported by Markides' study of three generations of Mexican Americans [24]. The family was found to be the dominant source of information and help in all generations. Moreover, women were the predominant source of advice regarding minor health problems, with the older generation relying mostly on their daughters.

Relationships among female family members, especially between mothers and daughters, could therefore form the basis of a community based family intervention where daughters (or other younger female relatives) are encouraged to promote screening behavior in their mothers. The underlying rationale is that the younger population of Hispanics is probably on average better educated and more knowledgeable about cancer risks and screening techniques. They also have more exposure to health screening information in their child bearing years through frequent doctor/clinic visits for maternal and child health services. We argue that a strong, supportive mother/daughter (or other younger female relative) relationship promotes the exchange of this information and provides encouragement to participate in mammographic screening.

### **Purpose of Study**

In order to design such an intervention, more information is needed on the screening behavior of elderly Hispanic women and how culturally specific values such as familism might be utilized to promote annual mammography [25,26]. Through a population based survey, the study will identify determinants of ever having a mammogram and having had a mammogram in the past two years, with a focus on factors unique to the Mexican American population that might reinforce or discourage screening behavior. Of particular interest is the negative influence of low acculturation found in other studies of health services utilization and the potential supportive role

of familism. Data is being collected that will assess the nature and extent of family networks and support and their influence on current screening behavior.

We are also gathering information that will evaluate the feasibility of developing and implementing an intervention that targets young Hispanic women and provides them with information on screening risks and benefits that they will be encouraged to relate to their mothers and older female relatives. These younger women will be exposed to screening information as they visit maternal and child health clinics for routine obstetric/gynecological services.

# Scope

The principal aim of this study is to conduct a population based survey of Mexican-American women age 50-74 years who reside in the counties of Galveston, Brazoria and Matagorda. Information is collected through a questionnaire, administered in face-to-face interviews, that contains questions on the subject's predisposition to seek screening mammograms, the availability and accessibility of those services and other factors that support or hinder screening behavior. It will also ascertain whether a woman has ever had a mammogram and if she has, whether she has had one in the past two years. Of particular interest in this study are the predisposing and reinforcing factors that are unique to the Mexican-American population, such as level of acculturation and strong family support. The survey is also collecting information on the proximity of daughters and other female friends and relatives that might be targets of a family oriented intervention through local maternal and child health clinics.

The following hypotheses will be tested with data from the survey:

1. Selected predictors of mammographic screening behavior in predominantly non-Hispanic populations will generalize to Mexican Americans. These include education, marital status and barriers to access, in addition to beliefs, knowledge and attitudes about breast cancer.

We hypothesize that mammographic use increases with educational attainment and income and decreases with distance or travel time from a screening facility. Use is also higher with being married, having insurance coverage and having a usual source of care.

Based on theoretical models of health behavior we expect that use will also be associated with knowledge of the risks and symptoms of breast cancer; attitudes about preventive care; beliefs about the efficacy of screening; concerns about radiation, embarrassment, pain and positive findings; and perceived susceptibility to breast cancer. Although there is no strong empirical evidence to support these associations from studies involving urban Hispanic groups, we plan to explore these relationships in a more rural population of Mexican American women.

2. Women with low levels of acculturation are less likely to have had a mammogram/had a mammogram in the past two years than women with high levels of acculturation.

We hypothesize that all dimensions of acculturation as well as the overall scale are significant predictors of not having a mammogram/having had a mammogram in the past two years. Language use and preference, however, will be the strongest predictors. Women who speak only Spanish have lower exposure to television media messages and written material on breast cancer. They also have greater difficulty in locating screening services and making an appointment.

3. Strong social support related to the family is associated with an increased likelihood of ever having a mammogram, after controlling for level of acculturation.

We hypothesize that strong family networks, in terms of number and frequency of contacts, are associated with a high likelihood of having a mammogram/having had a mammogram in the past two years. Functional social support, in terms of emotional and material resources from the family that are available to older women, also increases the likelihood of mammogram use.

Because familism and social support are negatively correlated with level of acculturation and because acculturation may be associated with low utilization of preventive health services we are controlling for level of acculturation to examine the independent effects of familism and social support on mammography screening behavior.

A particular focus of this study is the relationship between elderly women and their daughters. We hypothesize that intergenerational solidarity between mothers and daughters is a significant predictor of mammographic screening. We also hypothesize that: 1) among women who never had a mammogram, at least 75 percent would get one on the advice of her daughter and 2) among women who have had a mammogram, 25 percent will report "encouragement from daughter" as an important reason for having one.

A separate sub-study will be conducted to assess the validity of the mammogram self-reports. Two sources of information will be utilized to verify the mammogram reports: 1) records of the radiology facilities where subjects reported receiving mammograms and 2) Medicare billing files. By comparing self-reported mammography use to these other sources of data we will:

- 1) obtain estimates of the extent of over-reporting (or under-reporting) of mammograms in the first two years prior to the survey;
- 2) examine the relationship between patient characteristics and errors in self-reporting.

### **METHODS**

### **Study Population**

Our study population consists of Mexican American women age 50-74 years who reside in three southeast Texas counties: Galveston, Brazoria, Matagorda. The population is being

identified during the period of data collection from August 1997 through November 1997. Based on 1990 Census estimates, the total number of women in our study population is 3760.

The three counties stretch for 140 miles along the Gulf of Mexico and up to 100 miles from Houston in Harris county (see map in Figure 1). All three counties are designated non-metropolitan counties by the U.S. Bureau of the Census and are considered rural for health care delivery issues within the state [27]. Defined by the percent of persons living in rural areas, however, the degree of rurality varies from about 6 percent in Galveston County to 39 percent in Matagorda County. The counties also differ in the percent of their population reporting Mexican American ethnicity in the 1990 Census, from 12 percent for Galveston to 23 percent for Matagorda. The Hispanic population (which is largely Mexican American) in all three counties has roughly half the educational attainment and income of the non-Hispanics. In Galveston, the number of primary care physicians per 10000 population is 6.6, which is close to the ratio for the entire state (6.0) [27]. The ratio is lower for Matagorda (5.3) and Brazoria (3.8) counties.

# **Conceptual Framework**

The determinants of mammographic screening will be investigated in the framework of the PRECEDE-PROCEED ("predisposing, reinforcing, and enabling causes in educational diagnosis and evaluation") model [28], which incorporates concepts from Anderson and Aday's model of access to care [29] and Rosenstock's Health Belief Model [30]. It has been used in previous studies of health screening behavior [31-34]. The PROCEED framework provides the steps for implementation and evaluation.

In this study, we are utilizing phase 4 of PRECEDE where we examine factors that have a potential influence on mammographic screening. Numerous factors are seen to influence health behavior and PRECEDE aggregates them into three broad categories according to the strategies that might be employed to bring about change. Predisposing factors are individual attributes that motivate one to act and reflect personal preferences that serve to promote or inhibit health behavior. These include demographic characteristics such as age, and educational attainment as well as personal knowledge, attitudes, values, and perceptions of breast cancer and mammography.

Enabling factors pertain to the availability and accessibility of screening services. They are personal and community resources that enable a woman to obtain a mammogram. Enabling factors include insurance coverage for screening mammograms, available screening facilities and transportation services, and having a usual source of health care.

Reinforcing factors are external influences that support or hinder screening behavior. They include factors antecedent to screening that may affect a woman's seeking services. Or, they may influence subsequent (routine) use of screening mammograms through reinforcement or discouragement of the behavior. The attitudes and behavior of family, friends, and health care

providers are particularly important sources of reinforcement. Exposure to pamphlets and media messages that encourage breast cancer screening can also affect screening behavior.

Of particular interest in this study are the predisposing and reinforcing factors that are unique to the Mexican American population, such as level of acculturation and strong family support. The major focus of the research is determining whether these factors are associated with ever having had a mammogram and having had a mammogram in the past two years.

In the PRECEDE model, Phase 4 is the diagnostic phase of the planning process. Significant factors are identified and assigned priorities for focussing the intervention. Priorities are set based on the factor's relative importance, potential for change and available resources. Although this study is limited to Phase 4, we see our results feeding into Phase 5 - the development and implementation of a screening program for older Mexican-American women.

### **Power Analysis**

The specific aims require that we estimate the prevalence of mammography among Mexican American women ages 50 and over. Previous studies suggest rates as high as 30 percent and as low as 10 percent. Table 1 shows the sample sizes required for 90 and 95 percent confidence intervals of width 10 percent. We wish to have an 80 percent probability of covering the true prevalence rate, which is analogous to power in hypothesis testing. Calculations were done using the program PC-SIZE [35]. This means that if the 30 percent of Mexican American women in the survey area have had a mammogram, then a sample of 349 interviewed women will generate a 95 percent confidence interval of length 10 percent which contains 30 percent 80 percent of the time. Put differently, if we interview 248 women we are 90 percent confident the resulting interval from, for example, .25 to .35 will contain the true underlying mammography rate 80 percent of the time. The second major column of Table 1 reflects an adjustment for an 80 percent response rate and a 25 percent design effect due to cluster sampling. These adjustments inflate the required sample sizes by 56.25 percent. Thus we need to identify 616 Mexican American women aged 50-74 to obtain the equivalent of a simple random sample of 394.

Given an approximate combined sample of nearly 400 women we can project the probability of detecting significant predictors of mammography. In Table 2 various combinations of predictor distributions are shown for at least 80 percent power, two sided alternative ( $\alpha$ =0.05), and a base screening rate of .25. We have only considered predictor distributions which sum to 400, e.g. 100 and 300 (or less). Thus a shift from a screening prevalence of .25 to .4 will be detected with 80 percent probability for predictors which split 300 versus 100, such as the poverty variable. A shift of .2 can be detected for variables as small as 100 per level with 85 percent probability. With a sample of 322 with a 40 percent positive rate a shift in screening of 15 percent again has an 80 percent power. Thus our sample should address the expected predictors of hypotheses 1 and 2.

The nature and level of family contacts (hypothesis 3) are measured using social support scales from other investigators, the familism scale developed by Sabogal et. al. [20], and the associational, affectual and reliance scales used by Markides [24]. These are all quantitative scales with standard deviations smaller than those of the prevalence rates, hence the confidence intervals will be smaller.

# Sample Design

The goal of the survey is to obtain a representative sample of the Mexican American women 50-74 years of age residing in blocks or block groups of Brazoria, Galveston, and Matagorda counties. Described below is the procedure we used to select the sample with data at the block group level from the Bureau of the Census.

The 1990 census indicates the target population contains about 3760 women. Available block group (BG) data indicate these women are contained in a population of <5760 Hispanic females ages 50-74. The target counties contain 191,541 housing units of which 82% are occupied. Our budget allows for listing and enumerating 12,000 housing units to obtain a sample of 600 Mexican American women age 50 to 74. The objective of the sample design was to identify a random sample within the constraint of listing and enumerating 12,000 housing units.

The first step was to determine the density of Hispanic women 50-74. Block group data allowed us to classify block groups according to the ratio of: 1) total of Hispanics, 2) total Mexican-Americans and 3) Hispanic (but not Mexican-American) women 50-74 to the number of housing units. Block data does not provide information on 1) the number of total Mexican-Americans and 2) the number of Hispanics or Mexican-Americans by gender or age. Therefore, we estimated the number of eligible Mexican-American women in our sample based on the proportion of total Hispanic women 50-74 at the block group level and total Hispanics and number of housing units at the block level.

In the second step we eliminated all blocks which have no Hispanics at the block level. This was done manually from a printout of Hispanics and housing units for each block within the three county sampling area. This reduced by about half the number of housing units containing the target population.

In the third step we determined the target segment size. A segment is a contiguous collection of housing units that are listed and enumerated. Our target sample size was 600 of which we expected an 80% response rate or a total of 480 completed interviews. There were a number of options available to determine the proportion of rural and urban sample sizes, such as over sampling rural areas to obtain equal sample sizes of 300 rural and 300 urban, fixed sizes (200 rural + 400 urban, 100 rural +500 urban) or a proportional sample of target subjects to housing units (81 rural + 519 urban). We have chosen to use a proportional sample with 80% coverage of total households. This resulted in needing 430 rural subjects located in 13,326 units and 2,756 urban subjects in 52,861 units. To locate the proportion of this sample to yield 600 eligible subjects would require about 12,461 housing units, which satisfied our budget requirement.

For segment sizes, these proportions resulted in approximately 31 and 19 units to identify each eligible rural and urban subject, respectively. For practical reasons, we wanted to average 2 eligible women per segment. This suggested an average segment size of about 60 housing units.

Based on available data, an estimated number of Hispanic and Mexican-American females 50-74, the yield or number of housing units required for each eligible subject and the number of Mexican-American females 50-74 expected to be located in each segment was made at the block level.

In the final step we identified and selected the segments for enumeration. After eliminating blocks with no Hispanics, blocks were aggregated within counties, tracts and block groups. Beginning with the first eligible block, consecutive blocks were aggregated until approximately 60 housing units was reached. The corresponding number of Hispanics contained in those blocks was recorded. This resulted in the final listing of segments to be randomized for selection. As expected several blocks contained well over 60 units. These larger blocks were grouped into multiple segments that were "chunked" later if randomly chosen. For example, a block containing about 120 units would be considered 2 separately numbered segments. If one of those segment numbers was chosen, the multiple segments would be chunked to determine which housing units need to be enumerated.

All block aggregations were given a pre-specified segment number. From these a random number of segments was selected equal to the proportion of urban and rural housing units. These selected segments represented primary sample units (PSUs) to be used for enumeration and interviewing. There are 41 rural segments yielding 91 eligible subjects in 2637 housing units and 155 urban segments yielding 502 eligible subjects in 10,123 housing units. Note that since each segment and therefore each housing unit has a known probability of selection, this is a random sample of the eligible block group population.

### **Enumeration and Interviewing Procedures**

In the previous grant period (July 1, 1996 - June 30, 1997), a contract was developed and signed with Louis Harris and Associates to perform the fieldwork and data processing required for the survey. This includes listing and enumerating all housing units in the sample, then interviewing eligible subjects. This section describes the survey procedures.

Project staff at UTMB have provided maps of the designated segments for enumeration. These maps include a 1990 Census map and a Delorme map. The Census maps were purchased from the Bureau of the Census. Delorme maps were created using the Delorme Street Atlas USA software program version 3.0 for Windows. These maps are generally easier to read than the Census maps and may give more detail on street names.

Each segment has an identified starting point from which the interviewer will be expected to screen every household for an eligible subject. Where there have been sizable changes in the segment's housing stock, the map is referred back to Mr. Tony DiNuzzo or Dr. Daniel Freeman for clarification.

A subject is defined as eligible if she is female, self identifies as Mexican-American and is between the ages of 50 and 74. Four attempts to screen the household in an occupied unit are made. If no one is at home during any attempt, the composition of the household will be obtained from a neighbor or city directory. For women identified as eligible, interviewers attempt an interview immediately. Otherwise, at least five attempts (including screen) are made to contact and interview the woman unless she explicitly refuses.

### **Interviewer Training**

Louis Harris employed seven bi-lingual, female interviewers for this study. They have had extensive experience collecting health survey data as part of Dr. Markides study on the health of elderly Mexican-Americans.

The seven interviewers were brought to Galveston on June 30, 1997 for a training session that included the following topics:

background and general overview of the study
enumeration procedures
securing the interview (introduction, confidentiality, callbacks,
preventing and turning refusals)
probing guidelines
question by question instructions
informed consent

In addition, interviewers were given training in computer assisted personal interviews (CAPI). This is the method used by Louis Harris to administer the questionnaire and collect the data. Materials provided during the session included an interviewer training manual, question by question instructions that could be used as aids during the interview process, and a procedures manual for enumeration.

Following the session, procedures were field tested by two interviewers in five Galveston segments not included in the study sample. Information from the pre-test was reviewed by UTMB staff and several areas identified for further improvement before beginning the survey: correcting errors in the CAPI system, providing additional training to the interviewers in enumeration, and making changes to the questionnaire.

### **Problems Encountered With Field Work**

Our plan was to release the segments to Louis Harris in three replicates as defined by Dr. Daniel Freeman, co-investigator and survey statistician. Each replicate was representative of the entire sample. In terms of size, the first replicate represented 50% of the sample and the other two each represented 25% of the sample. With this method, if it looked like there would be more than 600 subjects, the final set of segments could be reduced or eliminated. If it looked like there might be

less than 600 eligible subjects, Louis Harris was to discuss the possibility of adding subjects with Dr. Freeman and also the cost implications of adding such segments.

In January 1998, Louis Harris informed us that their initial cost projections for the survey (\$143,000) overestimated interviewer productivity. As a result they grossly underestimated the direct costs of data collection (interviewer travel costs and time needed to complete each interview). Their personnel costs for project management and data processing were also much greater than initially projected.

They stopped collecting data before completing the first wave of the sample and gave us three options: 1) stop their survey operations permanently; 2) complete survey operations at an additional costs of \$100,000 or 3) complete 67% of the second wave for \$57,000.

After subsequent discussions with their survey staff and analyses of the data collected, we determined that they completed 178 of the 493 interviews we expected based on an 80% response rate. Our preliminary analyses also found that reducing the sample size would reduce our power to detect significant results.

The Louis Harris estimate of \$100,000 to collect these interviews was not affordable. Moreover, there were significant delays beyond what was initially projected in receiving the collected data. It was felt that these delays would continue if Louis Harris continued as the contractor.

We re-examined the productivity estimates from the interviewer listing sheets and the costs Louis Harris incurred for project management and data processing. It appeared that productivity varied by interviewer (about 4 of 7 interviewers were completing interviews at our projected rates for each segment) and that project management and data processing costs exceeded what we had experienced in managing a similar size survey in the past.

We therefore decided to complete the survey ourselves. We requested permission to do so from the Department of the Army. The Army granted us permission and also gave us a no-cost one year's extension (until August 31, 1999).

### Questionnaire

A questionnaire was developed during the previous grant year that collects information on measures needed to examine the relationships among mammography use and predisposing, enabling and reinforcing factors in the PRECEDE model. The questionnaire also includes questions that will be used to evaluate the feasibility of a family based intervention to encourage screening behavior. Below is a summary of the questions and scales used in the questionnaire.

# **Predisposing Factors:**

Demographic information is collected on age, education, and employment status. Education is measured as highest grade or year of regular school completed. Employment status is assessed in terms of whether the subject is currently employed, a homemaker, on disability or retired.

Acculturation is measured with the Hazuda acculturation scale [36]. The items measure proficiency in English, language usage, value placed on culture, attitude toward traditional family structure and interaction with mainstream society.

We use the SF-36 [37] developed by the Medical Outcomes Trust to measure health status. The SF36 includes scales that measure eight dimensions of health: physical functioning, role limitation, bodily pain, social functioning, mental health, role limitations due to emotional problems, vitality, energy or fatigue and general health perceptions. Changes in self-rated health status compared to the previous year are also assessed.

The subject's attitudes about preventive care are determined from her utilization of breast self exam, breast physical exam, and yearly routine check-ups. Knowledge of screening recommendations for breast cancer and the benefits of early detection are assessed with questions on the age and frequency women should have mammograms and chances of surviving breast cancer if detected early.

Her perceived susceptibility and risk is determined from how much she worries about getting breast cancer, her family/personal history of breast cancer and whether or not friends have had breast cancer. Fatalistic attitudes are measured with Cuellar's fatalism scale [38].

The impact of concerns about mammography on mammography use is assessed with a question on why a woman has not had a mammogram or not had one in the past two years.

# Enabling:

Income and measures of financial strain are measured with questions on income from all sources, reported difficulty meeting monthly bills and ability to make ends meet. Information on health insurance coverage is also collected. The subject's usual source of care is determined with questions on whether or not the subject has a regular doctor, a usual source of care and the type of usual source (if any).

Proximity to screening services is measured as distance and travel time between the subject's residence and the nearest screening facility. Screening facilities will be identified using a data base of mammographic screening facilities maintained the Texas Data Cancer Center. We measure access to transportation with questions on how subjects get to the doctor, how long it takes to get there and any difficulty arranging transportation.

## Reinforcing Factors:

Marital status is determined from the questions: Are you married, divorced, widowed or never married? For those ever married, subjects will be asked the length of time they have been married, separated, divorced or married. Marital satisfaction is measured with a scale from Markides three generations study. The influence of husband's health and his involvement with the subject's health is also assessed.

Social networks and social supports are measured in terms questions from the Berkman-Syme scale of social support [39]. Our specific measures of familism are living arrangement, number of children, frequency of contact with children and Sabogal et. al.'s [20] measures of the three factors in his familism scale - familial obligations, support from the family and family as referents.

We also employ scales from Markides' study of three generations of Mexican Americans to measure intergenerational association and reliance of older women on their daughters and/or other close younger female relatives. The association scale measures objective interactions with questions on how often the respondent (an older women) engages in activities with a close, younger female family member. Sources of help between the subject and the younger female relative is assessed with the reliance scale.

The influence of family members is further measured with questions regarding their involvement in the decision to have or not to have a mammogram, including whether any family members ever encouraged the subject to have a mammogram and whether she is more likely to get a mammogram if her husband or any other family member suggests she get one.

Risks for barriers to care will be determined based on whether the subject reports ever postponing getting medical care. In addition, for a subject who reports never having a mammogram or not having one recently, the interviewer will ask for reasons why - including barriers such as cost or lack of insurance.

### Mammography Use

Mammographic screening use is based on whether the subject ever had a mammogram and if so, whether she had one in the past two years. For a subject who reported she had a mammogram, the interviewer will ask what factors influenced her decision to get her most recent one. The questionnaire also collects information the date of the subject's most recent mammogram, why she had the mammogram (health problem or not) and at what facility she received it.

### **Spanish Translation of Questionnaire**

The questionnaire was initially translated by a member of the study staff (S. Black). To the extent possible, existing translations of questions that have been used in other surveys were incorporated into the initial version of the Spanish questionnaire.

This translation was reviewed by two persons whose primary language is Spanish - Magda Brown (a translator with UTMB's Language Assistance Office) and Dr. Marguerita Alegria (a member of the study's Advisory Group). It was also back translated by a member of the community whose primary language was Spanish and meets the eligibility criteria of our study (Mexican-American, age 50-74). Revisions were made based on Ms. Brown's and Dr. Alegria's recommendations and the results of the back translation. The revised version was pre-tested with a Spanish speaking woman (in the age range 50 to 74) from the local area. Further revisions were made based on this pre-test. A final version was constructed after the interviewer training session and field testing.

# Validity of Mammography Self-Reports

We are conducting a separate sub-study to assess the validity of the mammogram self-reports. This will be performed in the second year of the study. The methods for this sub-study are presented below.

The goals of our validation research are:

- 1) to obtain estimates of the extent of over-reporting (or under-reporting) of mammograms in the first two years prior to the survey;
- 2) to examine the relationship between patient characteristics and errors in self reporting.

In our evaluation of self-reports, we will investigate reporting errors within the 12 month and 24 month periods prior to the survey. Since we are primarily interested in screening mammograms, women who report having a mammogram for health problems are excluded.

Two sources of information will be utilized to verify the mammogram reports: 1) records of the radiology facilities where subjects reported receiving mammograms and 2) Medicare billing files. These sources of data and our approach for investigating reporting error is described in the following sub-sections.

## Radiology Facility Records

When a women has answered the questions on mammography we will ask for her consent to review her medical records (included in informed consent). Based on a study by Sudman et al.

[40] we estimate 84% will give us permission. For women who give their consent, we will review their medical records in the facilities where they report having had a screening mammogram. Documentation will be required that one was actually performed (e.g. radiology report) and not just ordered. UTMB is the major provider of screening mammograms in the three counties, performing 70% of all screening mammograms in this area (based on screening services reported in the Texas Cancer Center data base).

### Medicare Data

The Health Care Financing Administration maintains a series of statistical files containing billing information on all services provided to Medicare Beneficiaries. Medicare began covering screening mammograms in January 1991 under its supplemental insurance plan (Part B). Radiologists' claims (bills) for their professional fees can be used to confirm self reports of mammograms. Claims for screening mammograms will have a diagnosis code (in ICD-9-CM [41]) of V16.3, V10.3, V72.5, or V15.89 and a procedure code (in Current Procedural Terminology [42]) of 76092.

In terms of coverage, preliminary data from Dr. Markides study of elderly Mexican-Americans in the southwest indicate that approximately 88 percent of Mexican-American women age 65 to 74 are enrolled in Medicare and about 84 percent are covered under Part B, which pays for screening mammograms. Since 65 to 74 year olds will comprise about 28 percent of our sample, we estimate that about 24 percent (.28 x .84 x 100) of all our subjects will have Medicare Part B.

The Medicare data supplement the medical records review in several ways. First, for women who had a screening mammogram but cannot remember where, the physician claims could provide that information if Medicare paid for the mammogram. Second, since the data are extracted by the beneficiary's health insurance claim number, all mammograms paid by Medicare will be available for analysis whether or not they were provided by a Texas radiologist. Mammograms from facilities that are difficult to access (e.g. out of state) can therefore be verified. Third, the data provide an additional source of information on under-reporting. We will be checking the claims of all beneficiaries who consent to have their records reviewed, whether or not they report a mammogram in the survey. Fourth, the claims provide a back-up for cases where the medical records may have been lost or the procedure has not been recorded.

As a supplemental source of information, the Medicare data have some limitations. Previous research has found that a small percent of procedures do not appear in the claims files. Also, women who have their mammograms covered by some other source of funds or who participate in free community screening programs will not have claims for their mammograms in the data base.

# Sample Size for Validation

Based on the above estimates, we expect to have 414 subjects participating in our validation study: 0.84 (consenting proportion) x 493 (net interviews) = 414. This allows us to

project our likely confidence intervals for the agreement percentage. Several alternatives are shown for a 95% confidence interval in Table 3. If our agreement is poor ( $\approx 50\%$ ) then the interval width is 0.1. For good agreement (80%) it is slightly narrower (0.08).

Table 3	Confidence interval for				
	agreement $(n = 400)$				

Agreement	95% Cor	nfidence l	nterval
Proportion	lower	upper	Width
0.50	0.45	0.55	0.10
0.60	0.55	0.65	0.10
0.70	0.66	0.74	0.09
0.80	0.76	0.84	0.08
0.90	0.87	0.93	0.06
0.95	0.93	0.97	0.04
0.99	0.98	1.00	0.02

## Analysis

Our study's conceptual framework is based on Phase 4 of the PRECEDE model, where specific factors are identified and assigned priorities for focusing the

intervention. One goal of the analysis plan is to evaluate statistically the relative effects of the predisposing, enabling and reinforcing factors on mammographic screening. Other goals are to evaluate selected aspects of the survey methodology, test hypotheses of interest, and provide information for planning a culturally specific intervention for older Mexican-American women. To meet these goals, the data analysis plan has five objectives:

- 1) to evaluate the data and the sampling process;
- 2) to assess the agreement between self reports of mammography and documentation in the medical records and Medicare claims data;
- 3) to obtain estimates (and their standard errors) of mammographic screening by selected population characteristics;
- 4) to examine the effect of the predisposing, reinforcing and enabling factors on mammographic screening;
- 5) to summarize information on family structure and the use of health services that would be useful for program implementation.

# **Evaluation of Survey Methodology**

The first step in the analysis will be the evaluation of data and the sampling process. The data will be evaluated by univariate statistics and plots to search for unusual or outlying

observations. The sampling process will be evaluated by comparing the weighted population counts to those reported by the Bureau of the Census for the target counties (Table 2).

# Analysis Plan For Validation

For the subjects participating in the study, we will classify them first as "reported a mammogram in the 12 months prior to the date interviewed" or "reported no mammogram in the 12 months prior to the date interviewed." We will also classify them as "reported a mammogram in the 24 months prior to the date interviewed" or "reported no mammogram in the 24 months prior to the date interviewed." Both their medical records and claims will be checked for documentation of a screening mammogram in the given time period (12 months or 24 months). If either source verifies that at least one screening mammogram was performed in that period, then the self-report is considered "valid."

The data will be arrayed in two 2x2 tables, as shown in Table 4. The diagonal cells represent the cases with agreement between medical records/claims and self report for the two time periods. We will compute both Cohen's kappa and the simple percent agreement. The latter is more useful descriptively, and the former can be employed in logistic regression where the outcome is agree or disagree. In the logistic regression we will search for patient characteristics which may be associated with agreement. These characteristics include age, education, and insurance status, among others. The kappa statistic is given by  $\kappa = (p_a - p_o) / (1 - p_o)$ , where  $p_a$  is the observed agreement and  $p_o$  is the expected agreement under a hypothesis of

Table 4 Agreement data arrays at 12 and 24 months

Self Report 12 Months	Medical Records or Claims 12 Months		Self Report 24 Months	Medical Records or Claims 24 Months	
	Yes	No		Yes	No
Yes	a <sub>12</sub>	b <sub>12</sub>	Yes	a <sub>24</sub>	b <sub>24</sub>
No	$c_{12}$	$d_{12}$	No	c <sub>24</sub>	$d_{24}$

independence [43]. The observed agreement is  $p_i = (a_i + d_i)/(a_i + b_i + c_i + d_i)$ , where I = 12 or 24.

The validity study will result in estimates of measurement error. If measurement error exceeds 10 percent of the mean we will adjust our test statistics to reflect this [44].

# Estimates of Mammographic Screening

The next step in the analysis will be the preparation of prevalence estimates. These will use the inverse of the probabilities of selection to weight the data up to the county populations. Since a one stage cluster sample design (blocks form the clusters) was employed, the estimation of standard errors of the prevalence rates is a straight-forward exercise [45].

# Effects of Predisposing, Enabling and Reinforcing Variables

The conceptual framework based on the PRECEDE model has regular mammographic examination as an end point. This is a binary dependent variable with a variety of qualitative (categorical) and quantitative (continuous) predictor (independent) variables. The usual statistical model is based on a logistic distribution where the parameters are estimated with the usual likelihood ratio methods. We will do this in blocks where each domain of variables in the PRECEDE model is entered. The blocks are compared for statistical significance using a joint likelihood ratio test. In addition, the net information in each block will be obtained using Somer's D statistic which is a transformation of the area under a Receiver Operating Characteristic Curve. This follows the methodology of Freeman, Alegria, Vera, et al. [46]. This allows the comparison of non-hierarchical logistic regression models.

If one or more blocks are found significant, the specific factors within a block will be assessed using stepwise selection and significance testing. This allows us to examine which components of the blocks in the PRECEDE model need to be manipulated in a specific intervention. When variables of a specific block are being considered, the other, statistically significant, block will be held constant. After the detailed analysis of each block is completed, we finish the analysis by searching among all variables regardless of block membership. This purely statistical model will then be compared to what was obtained from the analysis of the fine structure of the blocks. These comparisons may suggest refinements of the PRECEDE model which would not otherwise be apparent. All analyses will be adjusted for the survey design effects through the use of SUDAN from the Research Triangle Institute.

Descriptive Information on Family Structure, Family Relationships and Use of Health Services

As noted in the Introduction, the motivation for this survey arises from a proposed intervention that would encourage screening behavior in older women through communication with their younger daughters, granddaughters and other female relatives. The younger women can be contacted and exposed to screening information as they visit maternal and child health clinics for routine obstetric/gynecology services and for their children's pediatric services.

Hence, another objective of the survey is to obtain descriptive information on family structure and family relationships. For example, we may find that strong family relationships is a good predictor of mammographic screening through the analysis process described above, but few

women may have such strong ties. The prevalence of certain characteristics about the older women is therefore critical to setting priorities and focusing our intervention. For this phase of the analysis, frequency counts (and percent distribution) will be generated for all the predisposing, enabling and reinforcing characteristics.

# **Preliminary Findings**

As noted in a previous section of this report, 178 interviews were collected by Louis Harris. A final data tape containing data on all the questions was received in June. In this section we report preliminary findings on the characteristics of the study sample, factors related to mammography use, and validation of mammography self reports.

# Characteristics of Study Sample:

Study subjects ranged in age from 50 to 74 years with a mean age of 59.5 years. Older women in the sample (65-74) accounted for 23 percent of the subjects (Table 5). In terms of education 71.3% had less than a high school education, 16.9 % had completed high school and 11.8% had years of schooling beyond high school. The majority of the sample was married (62.9%) and had some type of insurance coverage (63.5%) - either Medicare, Medicaid, or private. About 90% of the sample reported having a usual source of care. Most women (67.4%) were born in the United States.

When asked how often a woman of her age should get mammograms, 73.6% reported on a yearly basis. When asked when women should stop having mammograms, 78.1% reported no age limit.

Few subjects reported having had a recent check-up (14%), but the majority reported examining their breast for lumps (80.3%) and having a recent PAP smear (90.4%).

# Mammography Use:

Mammography use was higher than expected and in most cases exceeded the year 2000 goals. The year 2000 goals include: 1) increasing to 80% the percent of Hispanic women age 40 and older who ever had a clinical breast exam and mammogram and 2) increasing to 60% the percent of Hispanic women age 50 and older who received a clinical breast exam and mammogram in the past two years. In our sample, 79.2% reported ever having a mammogram and 86.5% reported ever having a clinical breast exam. About two-thirds the sample (65.7%) had a recent mammogram and 73% had a recent breast physical.

We examined the effect of selected population characteristics on mammography use by comparing the percent of users with a particular characteristics to the percent of non-users with that characteristic. Tests of significance were made at the .05 level.

For both measures of mammography use, users are younger and more likely to be married, have insurance and a usual source of care compared to non-users, but the differences are only significant with respect to usual source of care. Users are more likely to report women their age should have yearly mammograms and to report no age limit. These measures of knowledge had a significant effect on recent use, but not on ever having a mammogram. Recent use of physical breast exams is significantly related to both ever having a mammogram and having a recent mammogram. Users are more likely to examine their breast for lumps compared to non-users and the difference is significant for recent use.

Overall, users are more acculturated than non-users, and this relationship is seen across all the dimensions of acculturation except value placed on cultural origin. None of the differences is significant.

Users appear more likely to report that members of their family encouraged them to get mammograms or that they would be more likely to get a mammogram if their family encouraged them. The difference is significant for both measures of use when the family member is the one they rely on most for advice on health matters. Husbands appear to have the weakest effect on use, but marital satisfaction is significantly higher in the users compared to non-users.

The relationship between social support, as measured by family size and interaction, was not as hypothesized. Users had smaller households, fewer sons and daughters, and less contact with sons and daughters. These differences were significant for household size.

# Validation of Self Reports:

Preliminary validation of self report information was limited to only those subjects (n=42) who provided informed consent to examine medical records for mammography use from the University of Texas Medical Branch (UTMB). Radiology reports were examined regardless of whether subjects reported ever having a mammogram. Results for five women were incomplete since charts needed to be evaluated from other medical facilities in addition to UTMB.

Of the remaining 37 women, 26 reported having a mammogram within two years and 23 were confirmed through chart review (88.5%). Of the 11 who reported no recent mammograms, 8 reported never having a mammogram and 3 reported having a mammogram more than two years ago. All 11 were true negatives in the sense that no radiology report was found for any of them in the past two years. Overall, the agreement between self reports and radiology records was 89%.

### **CONCLUSION**

Based on the Statement of Work, the major activities in the second year are: 1) completing the field work (interviewing and validation) in months 1-6; 2) editing the data; 3) preparing the study's analytic file; and 4) performing statistical analyses. A summary of our progress with respect to each of these activities is given below.

### Field Work

Approximately 40% of the expected number of interviews were completed by Louis Harris over the period August 1997 through December 1997. Louis Harris ceased data collection at the end of December, citing cost overruns and higher than expected personnel costs for project management and data processing. UTMB project staff are now responsible for the filed work, which is what was initially planned in the original grant proposal. We have requested all records of the field work from Louis Harris and are now in the process of evaluating the sampling process and field operations. In addition, we have hired two experienced interviewers who participated in the first wave of the survey and have trained one local interviewer. Approximately 30 additional interviews have been collected during the first three weeks under UTMB staff's supervision.

### **Editing the Data**

Louis Harris interviewers collected data using the Computer Assisted Personal Interview (CAPI) data entry system (software program provided by Survey Craft, Inc.). A test file from the system containing 62 interviews was evaluated by UTMB staff within the first three months of data collection. Errors were identified in a number of the variables and were corrected in subsequent versions of the file. Another file containing the 178 observations was created and evaluated in March through June. As before, errors were identified and subsequently corrected in a succession of revised files.

## **Preparing Analytic File**

We began converting the raw data file to an analytic file in June. This process involves recoding the data into variables that can be used for analyses with the Statistical Analysis System (SAS).

# **Performing Statistical Analyses**

Preliminary analyses were performed on the 178 interviews. These aim of these analyses was to 1) describe the study sample in terms of selected demographic characteristics, screening knowledge and preventive attitudes/behavior and 2) make some initial observations about the relationship between selected variables hypothesized to influence screening behavior, particularly family relationships.

Our principal observations are that use of mammography (and breast physical exams) was higher than expected and is very close to or exceeds the year 2000 objectives set for Hispanic women. Demographic characteristics, including age, and acculturation have little impact on use. Knowledge and preventive health behaviors are significantly related to recent mammography use. Family relationships can reinforce screening behavior among married women through marital satisfaction and among all women through encouragement from the family member they rely on most for health advice.

We also initiated our data validation sub-study using subjects who indicated they received mammograms at UTMB. The agreement rate on preliminary data from 37 women was 89%.

In terms of our time line, we are one year behind schedule due to the delays in field work and data processing. Our project has received a one year no cost extension to complete the field work, validation of self reports and data analyses.

Table 1 Sample Sizes Required for an 80 Percent Coverage Probability by a ± 5 Percent Confidence Interval, With 25 Percent Design Effect and 80 Percent Response Rate

Table 1

Prevalence	Sample Size	Adjusted for Non Response And Design Effect	Sample Size	Adjusted for Non Response And Design Effect
10 percent	154	241	111	173
20 percent	267	417	190	290
30 percent	349	545	248	387
40 percent	394	616	281	439

Table 2 Power as a Function of Shift From Baseline and Predictor Distribution

Shift	N1	N2	Power	
.15	300	100	.8	
.2	101	100	.85	
.15	122	200	.8	
.2	101	200	.93	

Table 5 Distribution of Study Sample by Selected Demographic Characteristics, Screening Knowledge, Preventive Attitudes/Behaviors

Characteristic	Number of Women	Percent of Women	
Demographics			
Age			
50-64 65-74	137 41	77.0 23.0	
Educations			
<12 years	127	71.3	
12 years	30	16.9	
>12 years	21	11.8	
Marital Status			
married	112	62.9	
not married	66	37.1	
Insurance Coverage			
covered	113	63.5	
not covered	65	36.5	
Usual Source of Care			
Yes	161	90.4	
No	17	9.6	
Country of Birth			
United States	120	67.4	
Mexico	58	32.6	
Knowledge			
How often get mammogram			
Yearly	131	73.6	
Other	47	26.4	

139	78.1
39	21.9
havior	
25	14.0
153	86.0
143	80.3
35	19.7
161	90.4
17	9.6
	39 havior  25 153  143 35

Table 6 Percent of Mammography Users and Non-Users With Selected Population Characteristics

	Ever Had a Mammogram?			Had a Mammogram <2 yrs?		
Characteristic	Yes	No	p-value	Yes	No	p-value
Demographics						
% Age 50-64	77.3	76.7	.940	79.5	72.1	.269
% < 12 years education	70.2	70.0	.443	69.2	75.4	.536
% married	63.8	59.5	.621	64.1	60.7	.651
% with insurance	66.0	56.7	.335	65.8	59.0	.371
% usual source care	95.7	70.0	.001	96.6	78.7	.001
Knowledge						
% reporting women her age should have yearly mammograms	76.6	70.0	.590	79.5	62.3	.043
% reporting no age limit for mammography	80.1	73.3	.424	82.9	68.9	.026
Preventive Health Behavior Attitudes	rs/					
% recent breast physical	82.3	43.3	.001	88.0	44.3	.001
% examine breasts for lumps		73.3	.219	84.6	72.1	.047
Acculturation						
Mean Score Childhood English	2.61	2.51	.668	2.64	2.48	.359
Mean Score Adult						
English	9.16	8.84	.609	9.37	8.56	.089
Adult Language Use	28.54	27.76	.764	25.58	24.02	.376
Value Cultural Origin	6.28	6.68	.534	6.38	6.33	.914

Attitudes Traditional Family	14.49	14.16	.750	14.52	14.30	.721
Childhood Interactions Mainstream	4.21	4.16	.882	4.24	4.13	.691
Adult Interactions Mainstream	3.21	3.00	.396	3.27	2.98	.174
Total	68.44	67.11	.773	69.24	66.10	.370
Family Relationships						
% reporting family member ever encouraged mammogram	40.0	29.1	.240	40.7	26.5	.061
% reporting very likely/ somewhat likely to get mammogram if husband encouraged	76.7	76.5	.986	76.0	78.1	.812
mean marital satisfaction score	34.4	32.8	.206	34.8	32.7	.049
% reporting very likely/ somewhat likely to get mammogram if other relative encouraged	73.8	66.7	.125	76.1	64.8	.239
% reporting very likely/ somewhat likely to get mammogram if relative relies on most for health advice encouraged	83.7	69.7	.004	84.1	74.5	.030
mean number people living in household	2.82	3.87	.010	2.76	3.54	.003
Mean number sons	2.20	2.41	.478	2.30	2.44	.629

Mean number sons seen last month	2.03	2.14	717	2.21	2.16	.872
Mean number daughters	2.32	2.13	617	2.15	2.64	.060
Mean number daughters seen last month	2.20	1.78	209	2.06	2.09	.904

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